

Revisiting the Representation of Developmental Disabilities in Children's Picture Books: A Narrative Review

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Abstract: This research study revisits the theoretical frameworks in disability studies and the evolution over time from a medical-based model to a rights-based model. The change in academia also influences the cultural perspectives on Developmental Disabilities (DD). Despite the more inclusive social practices and attitudes among public, there lacks representation of DD in mass media and literature. Autism Spectrum Disorder (ASD) and Down syndrome (DS) are two types of DD that have high prevalence rate and rich academic research. Picture books, as a social product and a critical educational tool for promoting awareness in schools, institutions, and homes, however, are less researched in its representation of ASD and DS. The interplay and engagingness of quality picture books remain to be researched to provide implications for practitioners and publishers.

Keywords: Children, Developmental, Disabilities; Autism Spectrum Disorder, Down syndrome; Picture, books; Review.

1. INTRODUCTION

The paper revisits the culture of disability by looking at the definition of disability in different models of deficit-based medical model, social model and rights-based model. ASD and DD, as two prevalent types of DD, show different profiles in aspects of social relationship, physical appearances, motor skills and interactions. The advancement of scientific knowledge leads to the increasing diagnosed rate of DD and a surge in the number of representation DD in mass media and literature. The representation is not without problems. As the overarching term autism spectrum disorder (ASD) was proposed in 2013 in replacement of its various subtypes (American Psychology Association, 2013), autism differs from contributes to the difficulty in representing ASD in an all-encompassing way that reflects experiences that fit all in one work. While relatively lower prevalence rate of DS could account for the underrepresentation and simplification of representation in media.

Over time, changes in understanding of disabilities occur in terminology and inclusion (Prater and Dyches, 2008). Terminology used in medical and daily references for ASD and DD evolves and the language used to describe disability also complicates on the appropriateness to use person-first language (i.e. “the person with a disability”) and the identity-first language (i.e. “the disabled person”). Inclusive social practices replace the institutionalisation, and more humane way of inclusion is adopted and an acknowledgement of human rights is achieved by providing access to education, community, and employment (Miller and Katz, 2002).

Like mass media products, children’s picture books are socially constructed to serve specific purposes (Nodelman, 1981). Disability in children’s literature has been historically used as a metaphorical device, suggesting social and individual degradation and physical and mental anomalies. The potentially positive representation of disability can also cause “narrative erasure”, in a manner to eliminate of disability from texts and illustrations as something shameful and unpleasant. Picture books are characterized to convey meaning through two modes of texts and illustrations and their interaction, which could lead to non-synchronous and contradictory representations especially in presenting complex topic like DD. However, accurate and engaging quality picture books could serve to promote social awareness. Picture books

They have been acknowledged as powerful and useful tools for teaching complex or challenging content to children (Leininger et al., 2010; Prater et al., 2006) to promote awareness among siblings, students and public alike about DD and create a more inclusive environment.

The culture of disability

The history of disability is multifaceted, related to medical understanding and society's popular perception. The way disability is defined has taken on a deficit-based medical model and a later social and rights-based model. The label of disability is grounded in the medical model where disability is conceived as a personal tragedy orientated in individuals, rather than constructed by society (Vehmas, 2004). It is a problem that resides in the individual and requires correction for "normalisation" (Linton, 1998). The contradiction of desirable bodies and disabled bodies renders what Garland-Thomson (2004, p.779) called "the logical culture of euthanasia" where disabled bodies are either rehabilitated (to be "normalised") or eliminated (institutionalised or encouraged to die). The historical view of seeing disability as a sin and punishment leads to exclusion and destruction on them (Keith, 2001), with the example of the Nazi German's euthanasia programmes. Additionally, the biological inferiority presumed in the deficit-based model tends to blame an individual's failure in education and employment on their inability to "overcome" disability rather than acknowledging social obstacles and providing extra support (Linton, 1998).

The disability pride movements in the 1960s and the subsequent social model of disabilities challenged the medical culture. Instead of seeing disability as a personal tragedy, the social model acknowledges the barriers created by society and challenges its failure to meet a wide range of "physical, psychological and intellectual needs" (Asch, 1998, p.80; Johnston and Bonetti, 2001; Smith, 2004). Disability is regarded as a cultural and social product, constructed by science, charities, popular culture, and other multiple parties in order to present individuals with disabilities in particular ways and to reach different purposes (Snyder and Mitchell, 2006). However, the social approach is criticised for lack of focus on individual subjectivity and containing a normative concept that implies what is suitable for an individual and what is right as social arrangements (Vehmas, 2004). The rights-based model, acting a political extension of the social disability model, emphasises the civil rights of individuals with disabilities and their participation and self-agency in decision-making (Johnstone, 2001).

ASD, DS and representation

ASD is a developmental disability characterised by "persistent deficits in social communication and interactions in multiple contexts and restricted, repetitive patterns of behaviour, interests, or activities" (American Psychiatric Association, 2013). A wealth of literature shows that individuals with ASD have difficulties in social communication such as mentalising, perspective taking, understanding gesture, emotion recognition, and comprehending figurative language (Heasman and Gillespie, 2018; Pedreño et al., 2017; Happé, 1995; Mashal and Karirer., 2011; Roundblad and Annaz, 2010), but do not necessarily lack affective empathy and moral agency (Mazza, 2014; Kennett, 2002). Indeed, individuals with ASD are praised for having personal characteristics of honesty, loyalty, and attention to details (Schipper et al., 2016). Their preference to be alone does not necessarily equal to loneliness but instead a different perception and aspiration of friendship (Calder et al., 2013). Additionally, children with ASD are shown to have sensory processing differences. Hypersensitivity to noise, touch, and light can cause them to avoid touch and hug, crowd, show tolerance to only certain types of clothing or textures (Baker et al., 2008). Furthermore, children with ASD could be especially drawn to repeating patterns, whether these are spinning objects or activities that could add to sensory input such as rocking and swinging (Bodfish et al., 2000). Furthermore, ASD, as a spectrum containing a wide range of conditions, means some children might have limited speech, while some have no language challenge and may have savant skills in, for instance, puzzles, calendar calculation and memory (Pring, 2008). The outstanding visual memory and preserved rote memory (Mammarella et al., 2014; Bowler and Gaigg, 2008) observed in some individuals may contribute to their expectational navigation and fact memorising skills, but also cause sensory pain.

Down syndrome (DS) is one of the most commonly identified form of intellectual disability (ID). The genetic basis of DS is the triplication of chromosome 21 (Clarke and Faragher, 2014). A cluster of characteristics in physical appearances was found common, though not exclusive among children with DS. This includes a flat facial profile, a relative small mouth compared to the tongue, and relatively smaller and shorter than peers of similar age (ibid). Children with DS are reported to be slower at developing speech and language than children without DS (Eggers, 2018; Kent and Vorperian 2013), despite the considerable individual variations. A delay in speech production (Chapman and Hesketh, 2001) and a lower

speech fluency (Egges, 2018) are also found in children with DS, which could result in their difficulty of being understood (Kumin, 1994). Children with DS also face delays in motor skills development and physical fitness (Pitetti et al. 2013), such as running and dancing, but have relatively protected fine motor skills to carry out daily routines and academic activities at school. Sociability is widely considered to be an integral part of the DS characteristics (Knieps et al., 1994), while a wealth of research reveals that children with DS have difficulty in social cognition (e.g. emotion recognition in Katie et al., 2017 and social referring in Knieps et al., 1994) and maintenance of peer social network (Guralnick et al., 2011).

The increasing prevalence of diagnosed ASD leads to a spike in the number of published children's books on related topics, with an increase by 6833% over the last two decades between 1990 and 2010 (Gaffney, 2016). Savant skills are also discovered to be a popular topic, especially in films, although studies have pointed out that they could be over-represented and not credible (Dyches et al., 2001; Nordahl-Hansen et al., 2018). Osteen (2009) also suggests that misguided representations could result in a fundamental misunderstanding of ASD and further reinforce prejudice against those without savant skills. The representations of disabilities, argued by Snyder and Mitchell (2006), are not about disability "correctness" or simply more "positive" representation but instead are "more authentic and even oppositional" representations. However, Nordahl-Hansen, Øien, and Fletcher-Watson (2018) point out the nature of ASD, as a continuum covering complexity of conditions, contributes to the difficulty in portraying ASD in an all-encompassing way that reflects experiences that fit all in one work. Only viewing a combination of works could lead to the possibility of seeing the complexity of the continuum, if combined with experts' guidance (ibid).

DS, on the other hand, was vastly underrepresented in literature and media partly due to the lower prevalence rate and the less research attention compared to ASD and other types of DDs (Wishart, 2005). Also, because of social stigma and discrimination, there is infantilisation and simplification in media representations of people with DD who are typically portrayed as infantile and dependent and having little control over their lives and occupation (Renwick et al., 2013; Chen et al., 2012).

The evolving understanding of DD

From a holistic view, scientific knowledge and cultural perspectives in related policies and practices regarding DD have evolved over time. Prater and Dyches (2008) suggest the evolving change could be described across two areas: terminology and inclusion.

Terminology

Throughout history, the terminology around ASD and DS has gone through several changes. Changes in ASD include from being termed as brain damage to a neurological difference and from consisting of several subtypes to have an overarching term ASD. At Temple's time, autism was an unfamiliar term even to practitioners, and her doctor gave her the wrong diagnosis of brain damage in 1950, while contemporary books depict the correct diagnosis. Additionally, as the overarching term autism spectrum disorder (ASD) was proposed in 2013 to replace its subtypes, including "autistic disorder, pervasive developmental disorders not otherwise specified (PDD-NOS) or Asperger syndrome (AS), it was subtyped" (APA, 2013), ASD is used to refer to all on the spectrum.

The latest change in terminology about DS was proposed by the World Health Organization's in the 1970s to abandon the previous derogatory terms and replace them with "Down syndrome". "Down syndrome" is now used throughout medical and daily references. The language used to describe disability has evolved and is still evolving. There is an ongoing debate on whether it is preferable to use person-first language (i.e. "the person with a disability") or the identity-first language (i.e. "the disabled person"). However, Dunn and Andrew (2015) suggest that the focus should not be on the model used, but on acknowledging integrity and promoting respect. Indeed, they could be flexibly used when working on disability issues and interacting with persons with disabilities (ibid).

Inclusion

Apart from the breakthroughs in academia in explaining and destigmatizing disabilities, societal changes in practices and attitudes also contribute to the inclusion of those with disabilities in public domains. Societal treatment for persons with DD is shown to change in publications and media. The once prevailing institutionalisation can be seen in the picture book *The Girl Who Thought in Pictures* (2017). As time evolves, the humane way of inclusion or sense of belonging as an acknowledgement of human rights is achieved by providing access to education, community, and employment (Miller and

Katz, 2002; Keeffe, 2008). Substantive media and literature also present inclusive practices by showing acceptance among neighbourhood, access to mainstream schools with extra support, engagement in jobs portrayed in TV series like *The A world* (2016) and *Atypical* (2017) and films like *I am Sam* (2001) and *Stars on Earth* (2007). Participation in recreation like attending a summer camp is also portrayed in the picture book *My Friend has Downs Syndrome* (2008).

In the field of education, international and national registration protects the rights of education for individuals with disabilities (United Nations [UN], 2006; Riddell et al., 2012). Inclusion in practice requires knowledge and necessary skills from educators to effectively deal with peer relationships and create an inclusive environment in the mainstream classroom (Hodapp and Fidler 1999; Fidler, 2016; Young et al., 2017). The ever-developing breakthroughs in DS and ASD require educators' continued expertise, which could be achieved by effective continued professional development and training, which vice versa, predicts more positive attitudes towards inclusion (Lydon and King, 2009; Van Den Burgh et al., 2014; Hsien, Brown, & Bortoli, 2009). Collaboration with different stakeholders including parents, therapists, and school psychologists are adopted to support inclusion (Fidler et al., 2002; Young et al., 2017). Educators in literature are increasingly portrayed to be capable of providing tailored pedagogies to students with ASD in the book *All My Stripes* (2015) and implementing awareness talks before welcoming a child with DS in the book *My Friend Has Down Syndrome* (2008).

Disability through picture books

Picture books as social constructions

Children's picture books, as one form of children's literature, are unlike its adult counterparts and do not possess a tradition to address and question the challenging issues including gender, race and other cultural and social differences (Nikolajeva, 1996). The disability content in children's literature is selected and modified by adult publishers to serve specific purposes (Nodelman, 1981).

According to Mitchell and Snyder (2014, p. 47), disability is pervasively used in children's literature as a "narrative prosthesis", on which literature depends to characterise the characters against the norm and for "an opportunistic metaphorical device" (ibid). As a diversion from the norm of ableism, disability has often been metaphorically used to signify social and individual collapse, physical and mental anomalies. Classics, in particular, depend on disability for stereotypical characterisation. For instance, *Little Woman* typically portrayed Beth as a powerless invalid who is inadequate for womanhood. Classics also use disability to imply immorality, morally unacceptable behaviour and subsequent punishment metaphorically. Take *What Katy Did* as an example, Katy finally received her punishment of breaking her spine as she used the forbidden swing. Problematic characterisations in disability representation are also identified in contemporary children's books where individuals with disabilities are shown as angry, in danger or isolated, negatively portrayed as "poor little thing" for evoking pity and who lack autonomy and dynamic development (Ayala, 1999, p.103; Prater, 1999). However, these earlier studies mainly focused on the representations in texts, and few investigated those in illustrations, while the illustrations are also crucial for analysing picture books.

Picture books are characterised to convey meaning with the interplay of texts and illustrations (Nodelman, 1988). The positive meaning conveyed in one mode of the picture books could be problematic in another. Van Leeuwen and Leeuwen (2006) suggest that illustrations could entail meaning that is contradictory to that of the text, being non-existent and even prejudiced at times. For example, in Bailes's (2002) study, deaf characters are found to be inaccurately portrayed to be more attentive to sounds than visual elements, while the information is not contained in texts. However, little research on the representation of DD has studied the relationship between texts and illustrations.

However, the potentially positive portrayals of characters with disabilities could lead to "narrative erasure" (Aho and Alter, 2018, p. 304). It means disability is eliminated from the texts and illustrations and it is only revealed until the end of a book. The elimination of disabilities entails a message that despite being different, the child with disabilities could also be normal to be tolerated by others. This is especially dangerous because it could reinforce and circulate the ableism binary of "difference/sameness" and incline to return to positing disability to be something uncomfortable and shameful by framing disability as an individualised problem that could only be hidden (Aho and Alter, 2018, p304). Previous studies have investigated the picture books whose protagonists have physical disabilities. Aho and Alter (2018) observed that immobility portrayals of wheelchair users could be removed from visual markers by omitting the wheelchairs or using a dog or blankets to hide the legs, and Hughes (2012) questioned the eschewal of the word blind when

representing blindness. Developmental disabilities, in particular, are different from specific physically impaired disabilities and do not usually imply the disability status of the body (Osteen, 2009). Visual and metaphorical markers are important for examining whether the representation entails stereotyped or demeaning message.

Picture books for awareness promotion

Picture books are a crucial resource in the school and home settings and served as a teaching tool (Leininger et al., 2010; Prater et al., 2006), especially for teaching complex or challenging content to children in a nonthreatening way. The increasingly inclusive classroom requires awareness and support among students. Implementation of peer awareness through picture books helps develop acceptance and model pro-social behaviour to create an inclusive environment (Gaffney and Wilkins, 2016). Using such picture books also help students with disabilities “find” themselves and appropriate role models in the books. Additionally, as the rate of ASD, alone, amongst siblings, stands at 20% (Ozonoff et al., 2011), using picture books to teach siblings disabilities facilitates understanding and emotional growth. Despite the numerous benefits of using picture books for awareness promotion acknowledged in previous research, few have studied the quality features such as appropriateness and engagingness of the books. However, Moya Guijarro (2014) suggests the language and style of picture book should be appropriate for children’s age, and cognitive capacity of children should also be considered particularly when the picture books are targeted at children with disabilities (Prater and Dyches, 2008).

2. CONCLUSION

The paper provides a narrative review on disability culture and the evolving models used by society to define disability. ASD and DS, two forms of DD, vary in the prevalence rate, quantity of academic research and public attention drawn to. The representation in mass media and literature tend to partially or over represent certain aspects in individuals with ASD and under-represent or simply represent those with DS. Rapid development in science and medicine lead to changes in cultural perspectives of DD in social inclusion practices and attitudes, promoting understanding of DD and, to a certain degree, de-stigmatizes individuals with DD. A special perspective on picture books is also taken in this paper. Picture books are a crucial resource in educating DD in schools and homes and promote awareness. Nevertheless, more research remains to be done on representation on DD in pictures books and content analysis on the both texts and illustrations and their interaction to convey meaning.

3. LIMITATION

The validity of the information analysed in this paper are valid to the extent of validity in the claims made by the authors in the articles that have been reviewed. Further the study is limited in terms of scope of papers that were analysed. Typical of studies of this nature, that is constrained in terms of time and resources, it is not possible to review all the possible studies conducted in the area. If the number of articles had been expanded, other information unknown to the authors would have emerged. To that extent the paper is limited in scope.

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